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GINA, the ADA, and Genetic Discrimination in Employment

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The Genetic Information Nondiscrimination Act of 2008 (GINA)¹ was signed into law on May 21, 2008, after a 13-year struggle in Congress. GINA prohibits genetic discrimination in employment and health insurance, thereby supplementing existing federal protections against genetic discrimination in employer-sponsored group health plans contained in the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA)² and state laws prohibiting genetic discrimination in employment and individual health insurance.³

Although there have been very few documented instances of genetic discrimination in health insurance and employment, the fear of such discrimination has led many at-risk individuals to decline genetic testing in both the clinical and research settings. The findings section of GINA specifically states that federal legislation “is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”⁴

The approach and relative merits of GINA are subject to debate, but even its supporters recognize that GINA has major shortcomings.⁵ Three of the most commonly noted deficiencies are the following.⁶

First, GINA’s ban on genetic discrimination is not comprehensive. GINA does not apply to life insurance, disability insurance, long-term care insurance, or other potential uses of genetic information. Consequently, it is not clear that its limited protections will be sufficient to allay the fears of individuals currently dissuaded from undergoing genetic testing.

Second, GINA prohibits discrimination based on genotype, but not phenotype. Thus, GINA only applies to individuals who are asymptomatic. In the health insurance context, individuals are protected from discrimination based on their genetic risk of disease, but they are not protected if they develop the disease.⁷ In the overwhelming number of states, health insurance companies may lawfully raise the rates or refuse to renew the policies of individuals based on a change in their health condition.

Third, the employment provisions of GINA prohibit employers from requiring or requesting an individual to undergo genetic testing or disclosing the results of a genetic test as a condition of employment.⁸ Nevertheless, GINA does not affect a key provision of the Americans with Disabilities Act (ADA),⁹ under which an employer may, after a conditional offer of employment, lawfully require an individual to sign an authorization to disclose all of his or her health records to the employer.¹⁰ Because there is currently no feasible way to segregate genetic from non-genetic information in either paper or electronic health records, it must be anticipated that, notwithstanding GINA, many – if not most – custodians of health

records will continue the practice of sending requesting employers all of an individual's health records upon receipt of an authorization.¹¹

A previously unexplored but critical issue is how GINA's limited coverage and the ADA's limited coverage apply along the continuum from genotype to expressed disease. Although the same problem of determining when a condition is "manifested" exists under the health insurance provisions of GINA, this commentary is limited to genetic discrimination in employment.

ADA

The ADA is the principal federal law prohibiting discrimination, including employment discrimination, on the basis of disability. The ADA, however, does not prohibit *all* discrimination in employment based on disability because the ADA's definition of "an individual with a disability" is limited. The ADA uses a three-pronged definition of disability as being a physical or mental impairment that substantially limits one or more of the major life activities of an individual, a record of such an impairment, or being regarded as having such an impairment.¹²

On September 25, 2008, the ADA Amendments Act of 2008 was signed into law.¹³ The main purpose of the law was to overturn a series of Supreme Court decisions narrowly interpreting the ADA as applying only to individuals with severely disabling impairments.¹⁴ Mostly because of the narrow interpretation of who is covered, over 90 percent of individuals have lost their employment discrimination cases brought under the ADA.¹⁵ The essence of the new amendments is captured by the following rule of construction: "The definition of disability in this Act shall be construed in favor of broad coverage of individuals under this Act, to the maximum extent permitted by the terms of this Act."¹⁶

In 1995, the Equal Employment Opportunity Commission (EEOC) issued a non-binding interpretation of the ADA in which it declared that individuals who are discriminated against on the basis of "genetic information relating to illness, disease, or other disorders" are being regarded as having a disability.¹⁷ Most observers concluded that the EEOC's interpretation was unlikely to be followed by the courts because of the later, restrictive Supreme Court decisions. The ADA Amendments Act rejected those decisions, but did not address the issue of genetic discrimination or discrimination based on risk of future impairment. Perhaps the drafters of the ADA Amendments Act did not believe it was necessary to consider these matters in light of the enactment of GINA in May 2008.

Although the issue is now more clouded than ever, individuals with a genetic predisposition to future illness are probably not covered by the ADA. Nothing in the ADA Amendments Act indicates any congressional intent to overrule existing Supreme Court precedent holding that before an asymptomatic condition can be covered under the ADA, it must limit a major life activity.¹⁸ A provision in the ADA Amendments Act authorizes the EEOC to issue regulations implementing the definitions of disability,¹⁹ and it remains to be seen whether the EEOC will reconsider the issue of covering genetic predisposition under the ADA, especially because the EEOC is also charged with developing implementing regulations under GINA.²⁰

GINA

Both the health insurance and employment provisions of GINA expressly limit their protections to asymptomatic individuals who have been subjected to adverse treatment based on genetic information.²¹ GINA defines "genetic information" as information about an individual's genetic tests, the genetic tests of family members, and the manifestation of a

disease or disorder in family members.²² Of critical importance, GINA provides that it is not unlawful to use, acquire, or disclose medical information “about a manifested disease, disorder, or pathological condition of an employee . . . , including a manifested disease, disorder, or pathological condition that has or may have a genetic basis.”²³

Unfortunately, GINA does not define “a manifested disease disorder, or pathological condition.” GINA instead defines a “genetic test” as “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.”²⁴ The definition does *not* include “(1) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or (2) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.”²⁵

These definitions do not provide much guidance as to the types of tests considered genetic, let alone when a disease, disorder, or pathological condition is “manifested.”

Reading the ADA and GINA Together

As illustrated in Figure 1, the coverage of the ADA and GINA are mirror images at the extremes. In the context of genetic discrimination in employment, asymptomatic individuals are unlikely to be covered by the ADA, but they are expressly covered by GINA. Conversely, severely affected individuals are covered by the ADA, but they are expressly not covered by GINA. The greatest uncertainty is in the middle. Under the ADA, an individual with a mild, temporary, or presymptomatic condition does not come within the statutory definition of an individual with a disability.²⁶ Similarly, under GINA, an individual with a genetically based, biologically determinable difference beyond genotypic variation but short of phenotypic variation is unlikely to be protected.

The problems in interpreting GINA stem from the fact that the law is based on a scientifically dubious dichotomy between genetic and non-genetic information, tests, and disorders. It has been generally acknowledged by scientists for decades that virtually all human disease has both genetic and environmental components. New developments in proteomics, transcriptomics, metabonomics, epigenetics, and other fields have blurred the line between asymptomatic and symptomatic. The various biological processes by which a gene becomes expressed are still being elucidated. Increasingly sensitive biomarkers and sophisticated analyses of endophenotypes add further complexity to disease mechanisms. Regardless of the policy issues implicated by different definitions under GINA, the distinctions drawn in the statute are scientifically untenable today and are likely to be increasingly problematic.

Conclusion

The employment discrimination provisions of GINA take effect November 21, 2009,²⁷ and the EEOC is charged with issuing regulations implementing GINA by May 21, 2009.²⁸ One of the most important tasks for the EEOC is to devise practical, understandable, and scientifically compelling rules for determining what degree of biological response or symptoms constitutes manifestation of disease, thereby precluding an individual from coverage by GINA. Under any conceivable definition of “manifestation,” however, an individual will be too affected to be covered under GINA long before having a substantial limitation of a major life activity necessary to be covered under the ADA. Thus, if comprehensive protection against genetic discrimination in employment is to be achieved, Congress will need to amend one or both laws to eliminate the currently undefined,

significant gap in coverage. It is unclear whether the EEOC has the statutory authority or inclination to breach the divide by regulation.

Notwithstanding GINA's focus on *genetic* discrimination, the underlying social concerns are broader. As scientists develop increasingly sophisticated notions of human variability and disease prediction, policy-makers and the public need to decide what effect, if any, such information should have on access to societal opportunities, including health insurance and employment.

References

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7. *GINA* § 102(b).
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12. 42 U.S.C. § 12102(2).
13. Public Law 110–325, 110th Cong., 2d Sess. (2008).
14. *ADA Amendments Act of 2008*, §§ 2(b) (2) to (b)(5). Among the restrictive decisions mentioned by Congress are *Suton v. United Air Lines, Inc.*, 527 U.S. 471 (1999) and *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, 534 U.S. 184 (2002).
15. Hoffman, S. Settling the Matter: Does Title I of the ADA Work?. *Alabama Law*;
16. *ADA Amendments Act of 2008* § 3(4) (A).
17. *EEOC Compliance Manual*, vol. 2, EEOC Order 915.002, Definition of the Term “Disability,” at 902–45, reprinted in *Daily Lab. Rep.*, Mar. 16, 1995, at E-1, E-23.
18. See *Bragdon v. Abbott*, 524 U.S. 624 (1998) (asymptomatic, HIV-positive patient denied dental services in dentist's office was covered under Title III of the ADA because, for her, being HIV-positive was a substantial limitation on the major life activity of reproduction).
19. See *ADA Amendments Act of 2008* § 6(a).
20. *GINA* § 211.
21. *Id.*, at § 102, 210.
22. *Id.*, at § 201.
23. *Id.*, at § 210.
24. *Id.*, at § 201(7)(A).
25. *Id.*, at § 201(7)(B).
26. 29 C.F.R. § 1630.2(j).
27. *GINA* § 213.
28. *Id.*, at § 211.

Coverage of GINA and the ADA

	Asymptomatic	Biomarkers, Endophenotypes, Mild Symptoms	"Manifestation of Disease"
GINA	Yes*	?	No
ADA	No	No	Yes†

* Prohibits discrimination based on genetic information, which includes an individual's genetic tests, the genetic tests of the individual's family members, and family history.

† Prohibits discrimination based on an impairment that constitutes a substantial limitation of a major life activity.

Figure 1.
Coverage of GINA and the ADA